

History of the Arkansas Spinal Cord Commission

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October 1997 and revised in January 1999

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March 2004

1957 to 1977

In 1975, the Arkansas Legislature passed Act 311, aka 20-8-201-203, to establish an Arkansas Spinal Cord Commission. Many things in Arkansas and in the United States had happened during the 10 to 15 years preceding 1975 to make this possible, but primarily the legislation was the result of the untiring, unselfish and unpaid efforts of Jane Smith (Mrs. Maurice Smith, Jr.) who became interested in spinal cord injury (SCI) in 1957 when her mother sustained a cervical injury with quadriplegia. Mrs. Smith discovered the benefits of rehabilitation from Dr. Howard Rusk and she determined to make the benefits available to any Arkansan with a SCI.

Background

At the request of Mrs. Smith, on June 16, 1966, the entire Arkansas delegation in the U.S. Congress (John L. McClelland and J. W. Fulbright in the Senate and Wilbur D. Mills, James W. Trimble and E. C. Gathings in the House) signed a letter to Mary Switzer, the Commissioner of the Rehabilitation Services Administration, stating that they “enthusiastically endorse your (Ms. Switzer’s) proposal to establish a Regional Spinal Cord Center in the Hot Springs Rehabilitation Center.” The “Model System” program was still in the discussion phase at that time.

In 1970, the Rehabilitation Services Administration awarded the first Research and Demonstration grant to Arkansas to provide comprehensive care (from onset to death) to persons with SCI. This concept of specialized, comprehensive care proved to be very effective in reducing complications and costs. As a result, the Rehabilitation Act of 1973 provided funding for additional “Regional Model Systems” for SCI. Applicants for a Regional Model System Grant had to demonstrate that they could provide this lifetime comprehensive care with close coordination between acute care, rehabilitation and long-term follow up. In addition, the Act mandated that State Vocational Rehabilitation programs work more intensively with severely disabled individuals, such as those with spinal cord injuries.

Innovation Grant

In July 1973, the Arkansas Rehabilitation Services (ARS) was awarded a four-year “Innovation and Expansion Grant” to provide special services to spinal cord injured citizens with emphasis on employment. Walter “Buddy” Carmack was named as Director of this statewide Innovation Grant.

SCI Case Managers

One aspect of Arkansas’ Innovation Grant was the designation of specific vocational counselors to



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work with these severely disabled clients. One SCI counselor was assigned to each of the eight regions of the state. These counselors had much smaller case loads and were given considerable leeway in the services (including medical rehabilitation) that could be provided as part of extended evaluation.

However, the ultimate goal of this program for the severely disabled (as with all Vocational Rehabilitation programs) was to close the case as “successful” (i.e., employed) or “unsuccessful.” One of the fundamental objections to expanding Vocational Rehabilitation as the agency to implement a comprehensive SCI program in Arkansas was this policy requiring closure of a case within a limited period of time. After a case was closed, it was difficult and time-consuming to reopen it when new problems arose, especially if the new problem was medical and not vocational. It was obvious that a more medically oriented program was needed which could take care of the acute injury, rehabilitation and lifetime follow up for the prevention and treatment of complications.

Survey

Another goal of the Innovation Grant was to establish a registry of all spinal cord disabled persons in Arkansas, including spina bifida. The first step toward such a registry was a survey which was done in 1974 by the Spinal Cord Task Force of the Arkansas League of Nursing (Mrs. Jane Smith, Chairman), with the cooperation of Mrs. Betty Bumpers (wife of then Governor Dale Bumpers), numerous public and private agencies and a large group of volunteers. The survey was directed by Elaine Wilcox, PhD, who had conducted the only two previous statewide surveys in Nevada and Hawaii. Six hundred and two individuals with SCI were identified, plus 284 with spina bifida, for a total of 886 persons with a spinal cord disability in Arkansas. This information was useful in justifying the need for a spinal cord commission to the Legislature.

Medical Rehabilitation Facilities

Hot Springs Rehabilitation Center (HSRC) opened in 1962 in the former Army-Navy Hospital under the direction of ARS. It was primarily a residential

vocational training facility for the physically disabled, but a medical rehabilitation section was included because there was no existing hospital or medical program in Arkansas which could provide the necessary therapy to prepare a disabled individual for vocational training. However, clients had to be medically stable and have clear vocational potential to be admitted to HSRC. Referral to the Center was through the local vocational counselor and most physicians were not aware of the rehabilitation potential for spinal cord injuries or that such a program was available. Therefore, very few early spinal cord injuries were referred. Most referrals came about through Mrs. Smith's efforts. She visited any Arkansan with SCI that she heard about, told them what could be done and helped to smooth the way for admission.

Little Rock Baptist Hospital

On March 3, 1974, Baptist Hospital moved into the new Baptist Medical Center in West Little Rock, leaving vacant the old hospital on Marshall Street. After extensive review of the options, the Baptist officials decided that a Rehabilitation Hospital would make the best use of the old facility, and the hospital reopened on August 14, 1975, as the Arkansas Rehabilitation Institute. The hospital was equipped for SCI rehabilitation with the help of a grant of \$200,000 from ARS, as well as \$100,000 from the Spinal Cord Commission.

However, initial efforts to develop a comprehensive program were beset with many problems, especially physician turnover. It was not until November 1985, when Arkansas Rehabilitation Institute moved into a new facility on the campus of Baptist Medical Center that the SCI medical rehabilitation program really flourished. In 1989, the name was changed to Baptist Rehabilitation Institute (BRI).

Because there were no medical rehabilitation facilities for SCI in Arkansas, Dr. Stevenson Flanigan, Professor of Neurosurgery at UAMS, and Buddy Carmack, Coordinator of the Innovation Grant, arranged to send several individuals to The Institute for Rehabilitation and Research (TIRR) in Houston, TX, which was one of the first federally funded “Model Systems” for SCI. In

1974, there were four referrals to TIRR and in 1975 there were six. This was a major drain on Arkansas' limited funds since patients had to be transported via chartered plane. This rehabilitation plan was funded by Extended Evaluation funds from ARS, as well as private resources. The cost of sending patients out of state also helped to demonstrate to the Legislature the need for a comprehensive SCI program in Arkansas.

ASCC Established in 1975

It was at this stage that Mrs. Smith decided that the time was right to demonstrate the need to the Arkansas Legislature. She persuaded Dr. Howard Rusk of New York University's Institute of Rehabilitation Medicine, considered by many to be the "Father of Rehabilitation," to come to Little Rock to explain to the Legislature what could be done with a comprehensive program. Following his speech, plus the lobbying efforts of Mrs. Smith, Act 311 of 1975 to create the Arkansas State Spinal Cord Commission was passed unanimously in both the House and the Senate. The Commissioner of Arkansas Rehabilitation Services was designated as disbursing officer for all funds.

Commission Appointed

On July 17, 1975, the first Commission members were appointed and sworn in by Governor David Pryor. They were: Mrs. Patricia Birch (mother of a child with spina bifida), Roger Bost, M.D. (Pediatrician), John Bowker, M.D. (UAMS Orthopedist), Thomas Durham, M.D. (Orthopedist), Stevenson Flanigan, M.D. (UAMS Neurosurgeon), Ms. June Garner, R.N. (nurse), Marshall Purvis (consumer), Mrs. Jane Smith, Harold Thomas (consumer), and ex officio, Russell Baxter (Commissioner of ARS).

The initial goals were very ambitious, i.e., to develop a comprehensive program for all Arkansas residents with a spinal cord disability, regardless of cause, with services being available from the time of onset of the disability until death. The commissioners were dedicated to the concept of a comprehensive program and spent much time and effort trying to develop a plan of action. It was obvious that Arkansas could not pay for such a program alone, therefore, it would be necessary to apply for one of the SCI "Regional Model Sys-

tems" being funded by the Rehabilitation Services Administration.

Leadership Struggles

The first two years following formation of the Spinal Cord Commission were very chaotic, primarily in the efforts to develop a plan for the medical management. Each Commission member had a different concept of how the plan should be implemented, what should be included, where it should be located, and, even more important, who should be in charge. No hospital or physician group was willing to see another facility designated as the SCI Center. A major point of controversy centered around whether a Physiatrist (specialist in Rehabilitation Medicine) or an Orthopedist should direct the program.

In 1977, with the help of Russell Baxter, UAMS was awarded a grant of \$200,000 to establish a new Department of Rehabilitation Medicine. The position of Chairman of this department was offered to Bill Donovan, M.D., a physiatrist with a special interest in SCI. Unfortunately, this plan was defeated by the Chairman of the Department of Orthopedics, who thought an Orthopedist should be in charge of the program and Dr. Donovan went elsewhere.

New Consumer-based Commission

The disagreements over these issues became so intense that it seemed obvious that no compromise could be reached, so on February 26, 1977, the entire Commission was dismissed. Act 428 of 1977, aca 20-8-202, established a new consumer-based Commission with only five members instead of the original nine. On September 9, 1977, a new Commission was appointed, consisting of four of the original Commissioners, Dr. John Bowker, Mrs. Jane Smith, Mrs. Patricia Birch Livdahl, and Mr. Marshall Purvis, plus Mr. John Haskins (consumer) and Russell Baxter (ex officio).

Commission Membership

Act 428 specified that commission members must be "either spinal cord injured victims themselves or members of the immediate families of spinal cord injured victims, or persons with special knowledge of and experience with spinal cord

injuries and dysfunctions and who have demonstrated active involvement and interest in the fight against death and disability due to spinal cord injury and dysfunction.” This language effectively removed the commission from the immediate influence of the established medical community and placed an emphasis on meeting the needs of the client regardless of where the resources were located.

The redefined Commission has survived to the present day and has been effective in guiding the agency. Commissioners are appointed by the Governor for a term of ten years and receive no compensation. Meetings of the Commission are held quarterly with a Chair and Vice-Chair elected from their membership.

Case Management

Buddy Carmack was named as the first Executive Director of the Spinal Cord Commission in October 1975, but he continued to be the Director of the Innovation Grant, as well as Medical Coordinator at Hot Springs Rehabilitation Center. Although this was a very heavy load for one person, there were advantages to having a role in all three programs. During 1975 and 1976, while the controversy over medical care was raging, Mr. Carmack was quietly organizing a statewide case management program to coordinate services for the existing clients. The existing SCI Counselor positions were transferred from ARS to the Spinal Cord Commission for funding and their role expanded to “Case Manager,” rather than Vocational Counselor.

Case Managers were trained to be knowledgeable in all aspects of spinal cord disability, rehabilitation and independent living. They coordinated and provided needed services while working closely with the client, family members, medical professionals and other agencies. Not only are services provided immediately following diagnosis of spinal cord disability but for the client’s lifetime. Thus, Case Managers must be knowledgeable in a wide range of services.

Ten regional offices were established throughout the state to house 13 Case Managers. Each Case

Manager covers an area of Arkansas counties and is responsible for 100-200 cases. In 2001, the Little Rock based case manager position of Intake Coordinator was created to offer Commission services to newly injured/identified patients in local hospitals. Since most new clients come through Little Rock hospitals, the Intake Coordinator can process new referrals more easily and less expensively than out-of-town Case Managers. The focus of ASCC continues to be case management, client advocacy and lifetime follow up.

Registry

The original survey done in 1974 became the initial client list after the Commission was created, but it soon became obvious that an ongoing mechanism was needed to identify new injuries as early as possible after onset. Therefore, Act 330 of 1977, aka 20-8-206, was passed which established a Central Registry of Spinal Cord Disability to be administered by the Spinal Cord Commission, with mandatory reporting by health care professionals within five days after identifying a person with a spinal cord disability. This was the first legislatively mandated spinal cord disability registry in the United States.

1978 to 1987

Long Term Attendant Care

In 1981, a long term attendant care program was established for eligible clients with quadriplegia. The program allowed an individual to remain in the community with the assistance of a personal care provider. Designed to keep people out of nursing homes, the program provided assistance for 24 clients at about one-fourth the cost of maintaining a person in a nursing home.

Loan Closets

An equipment “loan” closet gradually came into being in the early 1980’s. The closet stores wheelchairs, cushions and supplies for loan or consumption by clients. Loaner wheelchairs and cushions provide mobility for clients while waiting for a prescribed chair or a chair to be repaired. The loan closet is stocked through agency purchases and private donations. In 2001 the agency established nine regional loan closets throughout the state.

These closets store a variety of supplies and equipment typically needed by clients. Coordinated by Case Managers, the expanded system results in greater client accessibility to equipment at reduced cost.

Medical eligibility

Criteria for medical eligibility for ASCC services were established in 1986. The four primary characteristics of spinal cord disability are paralysis, loss of sensation, loss of bowel control and loss of bladder control. To qualify for services an individual must have a pathology of the spinal cord resulting in at least three of these four characteristics. This eliminates minimally involved individuals who are not subject to all of the late complications of spinal cord disability and, thus, do not require such comprehensive care.

Fiscal Administration

Although ASCC was established as an independent agency reporting directly to the Governor and the Legislature, the Commissioner of the Arkansas Rehabilitation Service was designated as the disbursing officer to approve all expenditures and to sign all ASCC vouchers. This system worked fairly well despite occasional disagreements over priorities and it continued from 1975-1987. However, as the program stabilized, the Commission petitioned the Legislature for fiscal independence. Act 263 of 1987 authorized ASCC to select their own disbursing officer. Since that time the Executive Director has functioned as Disbursing Officer, with all expenditures approved by the ASCC Chairperson.

1988 to 2004

CDC Grants

Through a collaborative effort between ASCC Executive Director, Bruce Thomasson and Jim Wohlleb at the Department of Health, two grants from the Centers for Disease Control and Prevention (CDC), Disability Prevention Program and Division of Injury Control were applied for and received in 1988. The grants were awarded to states on a competitive basis and Arkansas was the only state to receive two grants. This was because ASCC already had an established registry and thus

a ready source of persons with spinal cord injury. The first grant was to document and reduce the incidence of pressure sores in Arkansas persons with spinal cord injury and the second grant was to establish a program of spinal cord injury surveillance in the state.

Although the grants by themselves were important, they also brought needed resources to the agency. Grant personnel brought new ideas and the additional funding bought needed equipment which was used to strengthen the agency's infrastructure. These changes would have been difficult to accomplish with the regular staff and funding. With two successful grants under its belt, ASCC was encouraged to seek further outside funding to meet its goals. Other CDC grants were applied for and awarded. In fact, ASCC has had a grant from or been a contractor to a CDC grant every year from 1988 to 2004.

Prevention and Education Efforts

Prevention of spinal cord injuries has always been a high priority and the agency has pursued outside funding to help finance these education efforts. From 1988 to 1993 the agency conducted a Spinal Cord and Head Injury Prevention program funded by the Arkansas Highway and Transportation Department and the National Highway and Transportation Safety Administration (NHTSA). The program presented a spinal cord and head injury prevention message emphasizing seat belt use, responsible alcohol use and to "Think First" before engaging in high risk behaviors. A wide variety of audiences were addressed but high school and junior college age students were targeted. In 1992 the program reached over 20,000 students.

In conjunction with the Arkansas Highway Safety Program and NHTSA, the Split Second Decision Program was established in 2002. This spinal cord injury and prevention educational program aims to change adult behavior regarding motor vehicle safety. The program targets young adults between the ages of 21-34 in schools, universities, employer safety meetings, vocational training facilities, and DUI/DWI classes. Case Managers, along with an individual with a spinal cord injury and an

Emergency Medical Technician or State Trooper, make a 45 minute presentation that relates true-to-life experiences and the consequences of making bad decisions. Participants are challenged to make positive decisions: Buckle Up, Drive Sober/Drug Free, Think First!

VISTA Activities

An active Volunteers In Service to America (VISTA) program was hosted by ASCC from 1993 to 2000. Volunteers coordinated the Education and Resource Center, designed the agency's web site, organized and expanded the equipment loan closet, recruited clients for a Peer Support Network, and established a wheelchair repair program. These volunteers developed new projects and programs which expanded the agency's capacity to provide new client services.

Resource Center

With funding from the Paralyzed Veterans of America, Educational Training Foundation, the Shirley McCluer, M.D., Education and Resource Center on Spinal Cord Injury was established in the Little Rock central office in 1990 with regional libraries in each Case Manager's office throughout the state. Named after the agency's first Medical Director, the resource center houses more than one thousand resources on spinal cord injury and diseases. Books, periodicals and video tapes are available for loan to clients and health professionals.

Spinal Courier

The first issue of the agency's *Spinal Courier* newsletter was distributed in September 1989. The newsletter was designed to be an educational tool to inform all clients of advances in medical care research and treatment, of educational, recreational and other opportunities related to spinal cord disability, of client related achievement and interest, and of ASCC and other organization-related activities. The first issue was a huge success and the newsletter has enjoyed continued popularity. In 2004, the quarterly *Spinal Courier* is distributed to over 2200 clients and 800 health care professionals and other persons interested in spinal cord disability.

Computerization of Registry and Agency

A requirement of the CDC Project was to report computerized data on Arkansas spinal cord injuries to CDC. This effectively forced the agency into the computer age to keep track of client case records electronically. The number of cases at the time was around 1000 and was proving to be increasingly difficult to keep up with using pencil-and-paper systems. Eventually information about all clients was computerized and a wide variety of management reports developed. These reports allowed the staff to better manage the client caseload and to allocate resources more effectively.

With more grants, and eventually state funding, computers were purchased for the entire staff by 1997 and most agency functions computerized. Internet access and electronic mail were added in 2002. The agency web site was created in 1998 and revised in 2003.

Perhaps the greatest advantage of the use of computers in the agency was the development of the Client Tracker in 1997. The Client Tracker is a computer program that allows a Case Manager to more effectively manage their caseload and to keep track of all the service dates for all their clients. This program encouraged the timely routine review of clients and reduced paperwork for the Case Managers.

Educational Conferences

The agency's first educational conference was held in June 1990 with 100 persons in attendance. Conferences give clients and their families the opportunity to hear disability-related speakers, to visit with other clients and families, and to meet with equipment providers.

In addition to the statewide conferences, regional miniconferences are conducted to allow those unable to travel to Little Rock to attend. Since 1990 over 3,000 people have attended ASCC educational programs.

Outdoor Recreation

Beginning in the early 1990's, the agency sponsored and the Case Managers conducted a variety

of regional recreation opportunities for clients and their families. Case Managers organized fishing derbies, boat cruises, fish fry and picnics.

Summary

The Arkansas Spinal Cord Commission has been in existence for over 25 years. There were many conflicts and controversies during the early years, but the Case Management program has survived and is now well established and successful. No other state or country has a comparable program.

The problem of dealing with spinal cord injury is not likely to go away. In fact, the changes in health care management that took place in the 1990's make it even more essential to have a program to ensure that disabled individuals know about the resources that are available for them.

As Mrs. Smith said at a meeting in 1979, "It was not the medical institutions and professionals who maintained the momentum for a comprehensive system of care, but rather a group of consumers that saw the fragmentation, and mess, that is created when the care of the SCI is put in the hands of multiple institutions, governed by multiple regulations, with no one taking overall responsibility."

2004 Status of the Commission

At the end of March 2004, the number of active cases on the registry was 2223—over two and a half times the original number in 1975. The number of active cases with spinal cord disability continues to increase each year. Scientific and medical advances have extended the life of spinal cord disabled individuals, so that, as a group, there are more new injuries than deaths of existing cases.

For Fiscal Year 2003 (July 1, 2002 through June 30, 2003) 2364 Arkansans with spinal cord disabilities received services from the Commission and fourteen Case Managers made 6482 visits to these individuals. Twenty-four clients received long term attendant care and four clients received short term attendant care. Sixty-six wheelchairs

were purchased and the homes of 24 clients were modified for wheelchair accessibility. In addition, 78 ramps were constructed for entry into the client's home. In total more than \$590,000 was spent for all purchased services of supplies, modifications, equipment, diagnostic fees and long term care.

A list of current Commission Members, Executive Officers, Case Managers, office locations, eligibility guidelines, services provided, special programs and other resources is available at the agency's web site: www.ar.gov/ascc.